

**Report of the Trustees and
Financial Statements for the Year Ended 31 March 2021
for
Noonan Syndrome Association**

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
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SY16 2NY

Noonan Syndrome Association
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for the Year Ended 31 March 2021

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Noonan Syndrome Association

**Reference and Administrative Details
for the Year Ended 31 March 2021**

TRUSTEES

Mrs K Ballard Chair
Miss S L Allsopp Deputy Chair
S Hoey Treasurer
Professor M A Patton FRCP Medical Adviser
I A Legg BA (HONS) ACIB
G Bowler (appointed 18.5.20)
B Carlton
Mrs J Dyer (appointed 18.5.20)
Ms A Reid - Kelly
Mrs G L Wilkes
Ms A Swift (resigned 27.6.20)

PRINCIPAL ADDRESS

PO Box 692
Blackburn
BB2 9RF

**REGISTERED CHARITY
NUMBER**

1140671

INDEPENDENT EXAMINER

Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

BANKERS

Barclays Bank PLC
Leicester
LE87 2BB

Charity Manager

Sandie Dent

Correspondence Address

PO Box 692, Blackburn, BB2 9RF

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2021

The trustees present their report with the financial statements of the charity for the year ended 31 March 2021. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

The objectives of the charity are to provide relief of all persons affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by all or any of the following means:

1. The provision of general advice, guidance and support services for persons suffering from Noonan Syndrome and related conditions (on the Ras/MAPK pathway), their families, dependents and carers;
2. The facilitation and promotion of research into the causes, effects, diagnosis, treatment and relief of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) with the useful results of research being disseminated for the benefit of the public;
3. The advancement in the education of the public in relation to the effects of Noonan Syndrome and related conditions (on the Ras/MAPK pathway) by communicating reports and disseminating information by any means or media concerning research work and studies undertaken by or on behalf of the charity.

In all that we do, our trustees have given careful consideration to the Charity Commission's general guidance on public benefit and have complied with the duty in section 4 of the 2011/2006 Charities Act.

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2021

ACHIEVEMENT AND PERFORMANCE

Charitable activities

The challenges which the Covid-19 epidemic has brought were beginning to make themselves clear towards the end of the 2019/2020 year, most notably by influencing the Trustees to postpone the Families Day and Activities Weekend. The main brunt of the restrictions brought on by the pandemic was, however, felt in 2020/2021. With the continuing uncertainty and the vulnerability of many members, the Families event had yet again to be postponed and is now scheduled for early October 2022.

Similarly, with the medical profession's focus on Covid, it was deemed inappropriate to proceed with the next round of invitations for research pump-priming. This will now take place during the 2021/22 year.

On a more positive note, discussions continued on how the charity could support the new specialist Rasopathies clinic at Great Ormond Street Hospital. It was agreed that the NSA would fund the costs of a part time specialist nurse for the clinic in collaboration with One Great Day, the main sponsoring charity for the development. Despite the postponement of the actual London Marathon, NSA had great support in the virtual Marathon led by Matthew Legg, son of the outgoing Chair of the NSA, Ian Legg and which he was running in memory of his brother Mark who had Noonan Syndrome.

During the lockdown, NSA took the approach of signposting reliable NHS/HM Government advice to members and by careful management of resources, maintained a good level of income and fundraising to ensure that the charity could come through the pandemic in good financial health. This was helped in no small way by the generous support received from members and particularly from Novo Nordisk who funded 6 months staff resource for the charity. Thanks must also go to Huddersfield Golf Club as NSA was their chosen charity which resulted in a donation of £4.75k.

The year also heralded notable changes in the management of the charity. Ian Legg, the chair of the charity from its inception announced that he would be standing down after 10 years. Longstanding trustee Katie Ballard took over as Chair towards the end of 2020 and one of her first tasks was to start the recruitment process for the role of Charity Manager as Peter Clarke, who had also been in that post for a decade, said that he would be looking to retire. After a recruitment made more challenging because of the pandemic restrictions, Sandie Dent was confirmed as taking up the role from early March 2021, although Peter would be staying on for some time in support.

The appointment of a new Chair provided the opportunity for the charity to look again at its aims and direction. A membership survey enabled the charity to collate the views of its major stakeholders, trustees and members on its key aims and vision. Trends in responses were identified and these were incorporated into a new 15-month plan for the charity as the year came to a close. The new developments are covered in more detail below.

FINANCIAL REVIEW

Financial position

The statement of Financial Activities shows a surplus for the year of £32,321(2020: £554), and reserves now stand at £94,177 (2020: £61,856).

Reserves policy

The charity does not have a separate formal policy on Reserves but following Board discussions, the Chair, Treasurer and Charity Manager follow a policy based on achieving free reserves of a minimum of between 3 and 6 months' operating costs including those associated with the cost of a part time charity manager.

The charity has an established and appropriate financial management system which is regularly reviewed by the Board and put into day to day practice by the Charity Manager, Charity Treasurer, Finance Officer together with the Chair of Trustees.

Free reserves which equate to net current assets (excluding restricted funds) amount to £67,506 (2020: £51,840).

FUTURE PLANS

The NSA, as with many other charities, faced uncertainty at the start of 2020/21 as the Covid-19 pandemic took hold. Because of the vulnerable status of members and some trustees, face-to-face activities could not be delivered even outside of government-mandated lockdowns. Plans for 2020/21 were changed, and continued to change throughout the year, but the overall priorities and aims of the charity did not. A key strength of the Board during this year has been its ability to revise plans to navigate that uncertain and changing landscape, whilst maintaining the core objective of supporting members and planning for the future.

Future plans include:

- delivering a series of online medical webinars during 2021 in place of the Families Weekend;
- funding two clinical research projects and one social research project;
- taking advantage of the charity's robust financial position to improve systems and processes, including investing in new technology; and
- further developing the charity's strategic plan.

Key strategic objectives include increasing membership, income and diversity of income, and increasing the range of support activities available to members (i.e. holding regional events). As the charity's membership grows, so the activities and resource to deliver them need also to grow. Managing this growth in a safe and positive way will be a key focus during 2021/22.

At the time of writing this report, we are now 21 months into the pandemic and still navigating an uncertain landscape. Reflecting back on the 2020/21 year and achievements the charity made despite the difficult environment, it is clear that the solid financial position at the start of the reporting period put the charity in a strong position to survive, adapt, and even thrive during the challenging year to come.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Recruitment and appointment of new trustees

Trustees are elected by way of a resolution of the Charity at the Annual General Meeting. The Trustees also have the power at any time, and from time to time, to appoint any person to be a Trustee [subject to certain restrictions], either to fill a casual vacancy or as an addition to the existing members of the Board of Trustees but so that the total number of Trustees does not exceed any maximum number fixed in accordance with this Constitution. Any Trustee so appointed shall hold office only until the next following Annual General Meeting, and shall then be eligible for re-election.

Organisational structure

The charity is organised so that the trustees meet regularly to manage its affairs. Full Trustee Board meetings are held at least four times per year with other meetings held as required, both face to face and by conference call or internet.

There is an Annual General Meeting held for all the members of the charity at which Trustees are elected or confirmed.

The part time Charity Manager undertakes most of the day to day operations of the charity. In addition to a Chair, the trustees have appointed a Deputy Chair, Sharon Allsopp, and a Treasurer, Steve Hoey

Risk management

The trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. It has an agreed set of financial procedures and policies, practices and guidance to cover its activities, including the reserves policy set out above.

Noonan Syndrome Association
Report of the Trustees
for the Year Ended 31 March 2021

Approved by order of the board of trustees on 22 January 2022 and signed on its behalf by:

Mrs K Ballard - Trustee

Independent examiner's report to the trustees of Noonan Syndrome Association

I report to the charity trustees on my examination of the accounts of Noonan Syndrome Association (the Trust) for the year ended 31 March 2021.

Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Thomas Landers BA FCA
Institute of Chartered Accountants in England & Wales
Morgan Griffiths LLP
Chartered Accountants
Cross Chambers
9 High Street
Newtown
Powys
SY16 2NY

22 January 2022

Noonan Syndrome Association

Statement of Financial Activities
for the Year Ended 31 March 2021

		Unrestricted fund £	Restricted funds £	31.3.21 Total funds £	31.3.20 Total funds £
	Notes				
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	38,821	1,655	40,476	52,160
Charitable activities	3				
Support Network		-	25,820	25,820	-
Total		<u>38,821</u>	<u>27,475</u>	<u>66,296</u>	<u>52,160</u>
EXPENDITURE ON					
Charitable activities	4				
Research		3,384	-	3,384	3,699
Support Network		11,872	10,820	22,692	39,268
Awareness		7,899	-	7,899	8,639
Total		<u>23,155</u>	<u>10,820</u>	<u>33,975</u>	<u>51,606</u>
NET INCOME		<u>15,666</u>	<u>16,655</u>	<u>32,321</u>	<u>554</u>
RECONCILIATION OF FUNDS					
Total funds brought forward		51,840	10,016	61,856	61,302
TOTAL FUNDS CARRIED FORWARD		<u><u>67,506</u></u>	<u><u>26,671</u></u>	<u><u>94,177</u></u>	<u><u>61,856</u></u>

The notes form part of these financial statements

Noonan Syndrome Association

Balance Sheet
31 March 2021

	Notes	31.3.21 £	31.3.20 £
CURRENT ASSETS			
Debtors	10	10,911	10,058
Cash at bank		83,986	52,602
		<u>94,897</u>	<u>62,660</u>
CREDITORS			
Amounts falling due within one year	11	(720)	(804)
		<u>94,177</u>	<u>61,856</u>
NET CURRENT ASSETS			
		<u>94,177</u>	<u>61,856</u>
TOTAL ASSETS LESS CURRENT LIABILITIES			
		94,177	61,856
NET ASSETS		<u>94,177</u>	<u>61,856</u>
FUNDS	13		
Unrestricted funds		67,506	51,840
Restricted funds		26,671	10,016
TOTAL FUNDS		<u>94,177</u>	<u>61,856</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 22 January 2022 and were signed on its behalf by:

K Ballard - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income recognition

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. DONATIONS AND LEGACIES

	31.3.21	31.3.20
	£	£
Donations	38,023	50,397
Gift aid	2,453	1,763
	<u>40,476</u>	<u>52,160</u>

Noonan Syndrome Association

**Notes to the Financial Statements - continued
for the Year Ended 31 March 2021**

3. INCOME FROM CHARITABLE ACTIVITIES

		31.3.21 £	31.3.20 £
Grants	Activity Support Network	25,820	-

Grants received, included in the above, are as follows:

	31.3.21 £	31.3.20 £
Vinci UK Foundation	15,000	-
Novo Nordisk Limited	10,820	-
	<u>25,820</u>	<u>-</u>

4. CHARITABLE ACTIVITIES COSTS

	Direct Costs (see note 5) £	Grant funding of activities (see note 6) £	Support costs (see note 7) £	Totals £
Research	3,146	-	238	3,384
Support Network	14,153	7,743	796	22,692
Awareness	7,342	-	557	7,899
	<u>24,641</u>	<u>7,743</u>	<u>1,591</u>	<u>33,975</u>

5. DIRECT COSTS OF CHARITABLE ACTIVITIES

	31.3.21 £	31.3.20 £
Telephone	895	960
Postage and stationery	2,584	3,040
Promotional material	-	1,737
Sundries	640	1,267
Family day	165	26,927
Travel expenses	296	368
Computer & IT support costs	70	1,003
Charity Manager	16,491	14,425
Administration costs	3,500	-
	<u>24,641</u>	<u>49,727</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2021

6. GRANTS PAYABLE

	31.3.21 £	31.3.20 £
Support Network	7,743	-
The total grants paid to institutions during the year was as follows:		
	31.3.21 £	31.3.20 £
Great Ormond Street Hospital	7,743	-

7. SUPPORT COSTS

		Governance costs £
Research		238
Support Network		796
Awareness		557
		<u>1,591</u>
Activity	Basis of allocation	
Management	Based on time	
Governance costs	Based on time	

8. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2021 nor for the year ended 31 March 2020.

Trustees' expenses

During the year one trustee was reimbursed for travelling expenses amounting to £198 (2020 nil).

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	52,160	-	52,160
EXPENDITURE ON			
Charitable activities			
Research	3,699	-	3,699
Support Network	28,768	10,500	39,268
Awareness	8,639	-	8,639
Total	<u>41,106</u>	<u>10,500</u>	<u>51,606</u>
NET INCOME/(EXPENDITURE)	<u>11,054</u>	<u>(10,500)</u>	<u>554</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2021

9. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted funds £	Total funds £
RECONCILIATION OF FUNDS			
Total funds brought forward	40,786	20,516	61,302
TOTAL FUNDS CARRIED FORWARD	<u>51,840</u>	<u>10,016</u>	<u>61,856</u>

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.21 £	31.3.20 £
Prepayments and accrued income	2,453	1,763
Prepayments	8,458	8,295
	<u>10,911</u>	<u>10,058</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.3.21 £	31.3.20 £
Other creditors	720	804
	<u>720</u>	<u>804</u>

12. ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted fund £	Restricted funds £	31.3.21 Total funds £	31.3.20 Total funds £
Current assets	68,226	26,671	94,897	62,660
Current liabilities	(720)	-	(720)	(804)
	<u>67,506</u>	<u>26,671</u>	<u>94,177</u>	<u>61,856</u>

13. MOVEMENT IN FUNDS

	At 1.4.20 £	Net movement in funds £	At 31.3.21 £
Unrestricted funds			
General fund	51,840	15,666	67,506
Restricted funds			
Noonan Syndrome Research Fund	-	1,655	1,655
Families Event	-	15,000	15,000
The Andrew Family Research Fund	10,016	-	10,016
	<u>10,016</u>	<u>16,655</u>	<u>26,671</u>
TOTAL FUNDS	<u>61,856</u>	<u>32,321</u>	<u>94,177</u>

Noonan Syndrome Association

Notes to the Financial Statements - continued
for the Year Ended 31 March 2021

13. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	38,821	(23,155)	15,666
Restricted funds			
Noonan Syndrome Research Fund	1,655	-	1,655
Families Event	15,000	-	15,000
Support costs	10,820	(10,820)	-
	<u>27,475</u>	<u>(10,820)</u>	<u>16,655</u>
TOTAL FUNDS	<u>66,296</u>	<u>(33,975)</u>	<u>32,321</u>

Comparatives for movement in funds

	At 1.4.19 £	Net movement in funds £	At 31.3.20 £
Unrestricted funds			
General fund	40,786	11,054	51,840
Restricted funds			
The Andrew Family Research Fund	10,016	-	10,016
Eve Martin Fund	500	(500)	-
The National Lottery	10,000	(10,000)	-
	<u>20,516</u>	<u>(10,500)</u>	<u>10,016</u>
TOTAL FUNDS	<u>61,302</u>	<u>554</u>	<u>61,856</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	52,160	(41,106)	11,054
Restricted funds			
Eve Martin Fund	-	(500)	(500)
The National Lottery	-	(10,000)	(10,000)
	<u>-</u>	<u>(10,500)</u>	<u>(10,500)</u>
TOTAL FUNDS	<u>52,160</u>	<u>(51,606)</u>	<u>554</u>

The Andrew Family Research Fund:

13. MOVEMENT IN FUNDS - continued

This is to fund medical research directly relevant to Noonan Syndrome.

14. RELATED PARTY DISCLOSURES

During the year the trustees made donations to the charity totalling £2,053 (2020: £3,430).

Noonan Syndrome Association
Detailed Statement of Financial Activities
for the Year Ended 31 March 2021

	31.3.21 £	31.3.20 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	38,023	50,397
Gift aid	2,453	1,763
	<u>40,476</u>	<u>52,160</u>
Charitable activities		
Grants	25,820	-
	<u>66,296</u>	<u>52,160</u>
Total incoming resources		
	66,296	52,160
EXPENDITURE		
Charitable activities		
Telephone	895	960
Postage and stationery	2,584	3,040
Promotional material	-	1,737
Sundries	640	1,267
Family day	165	26,927
Travel expenses	296	368
Computer & IT support costs	70	1,003
Charity Manager	16,491	14,425
Administration costs	3,500	-
Grants to institutions	7,743	-
	<u>32,384</u>	<u>49,727</u>
Support costs		
Governance costs		
Indemnity insurance	781	751
Accountancy and legal fees	810	1,128
	<u>1,591</u>	<u>1,879</u>
Total resources expended	<u>33,975</u>	<u>51,606</u>
Net income	<u><u>32,321</u></u>	<u><u>554</u></u>

This page does not form part of the statutory financial statements